DOCUMENT RESUME

ED 372 572 EC 303 205

AUTHOR	Sturtevant, Judith; Elliott, Sandra
TITLE	Respite for Families with Children Experiencing a Serious Emotional Disturbance.
INSTITUTION	ARCH National Resource Center for Crisis Nurseries and Respite Care Services, Chapel Hill, NC.
SPONS AGENCY	Children's Bureau (DHHS/OHS), Washington, DC.; North Carolina State Dept. of Human Resources, Raleigh. Div. of Mental Health, Mental Retardation and Substance Abuse Services.
PUB DATE	May 94
CONTRACT	90-CN-0121
NOTE	7p.
PUB TYPE	Information Analyses (070)
EDRS PRICE	MF01/PC01 Plus Postage.
DESCRIPTORS	*Child Caregivers; *Emotional Disturbances; *Family Problems; Legal Responsibility; *Needs Assessment; *Program Development; *Respite Care; Severe Disabilities
IDENTIFIERS	*Family Needs

ABSTRACT

This fact sheet summarizes issues in the provision of respite services for families with children suffering from severe emotional disturbances. Background information supports the unmet need for respite care services to families caring for such children at home. A definition of "serious emotional disturbance" is provided and typical characteristics of such children are listed. The difficulties families have finding appropriately trained respite providers is stressed. Program developers are urged to pay close attention to the referral process, to matching of respite providers and families, to liability concerns, to training respite providers (a basic training sequence is outlined), and to program evaluation. The role of the state administration, especially of a state planning committee to oversee respite services is briefly addressed. (DB)

****
* Reproductions supplied by EDRS are the best that can be made *
* from the original document. *
****

ED 372 572

ARCH Factsheet Number 34, May, 1994

U.S. DEPARTMENT OF EDUCATION
Office of Educational Research and Improvement
EDUCATIONAL RESOURCES INFORMATION CENTER (ERIC)
This document has been reproduced as received from the person or organization originating it.
Minor changes have been made to improve reproduction quality.
Points of view or opinions stated in this document do not necessarily represent official OERI position or policy.

Access to Respite Care and Help
ARCH National Resource Center Coordinating Office
Chapel Hill Training-Outreach Project, 800 Eastowne Drive, Suite 105, Chapel Hill, NC 27514
Phone: 1-800-473-1727 or (919) 490-5577; FAX: (919) 490-4905
Human Services InterNet/SpecialNet Username: NC.CHOUTREACH

Respite for Families with Children Experiencing a Serious Emotional Disturbance

Background

In 1982, Jane Knitzer in her book, *Unclaimed Children*, noted that two million of the three million children and youth experiencing a serious emotional disturbance, and their families, in this country were not receiving adequate services. Ten years later, the percentage of families receiving services has not increased substantially. According to The National Mental Health Association and The Federation of Families for Children's Mental Health (1993), 66 - 80% of children with a serious emotional disturbance are not receiving appropriate services. For many families, the only means of getting services has been to give up custody of their child or place their child in an institution. The cost to families and society for this approach has been high.

According to a 1992 survey by the National Mental Health Association, the highest priority for better serving this population of children is to develop

> *a range of appropriate school and community-based service options for children with serious emotional disturbance in all communities. (In particular, intensive community and family-based services, after-school programs, summer programs and respite care [Editor's emphasis].)*

Respite, temporary relief for caregivers and families, should be provided as a regular component of family support services. As such, respite can be provided to families on either a planned or emergency basis. Respite allows families the time they need to renew their energies and continue caring for their children at home.

Since the writing of *Unclaimed Children*, research and training has continued to demonstrate that these children and youth have legitimate and long-ranging mental health needs. It behooves the service delivery system to acknowledge the needs of families with a child or youth experiencing a serious emotional disturbance and then work with them, and on their behalf, to provide individualized, flexible, family-driven services.

Definition

Section 1912(c) of the Public Health Service Act, as amended by Public Law 102-321 defines children with a serious emotional disturbance as those who

1) are from birth to age of majority,
2) have had a diagnosable mental, behavioral, or emotional disorder of sufficient duration to meet diagnostic criteria specified within the *Diagnostic and Statistical Manual of Mental Disorders:* DSM-III-R,
3) that has resulted in functional impairment which substantially interferes with, or limits, one or more major life activities.

According to the Center for Mental Health Services, functional impairment is defined as difficulties that substantially interfere with or limit role function in one or more major life activities. This may include an inability to eat, bathe, or dress oneself, or an inability to function effectively in social, family, or educational contexts.

EC 303205

Characteristics

The National Information Center for Children and Youth with Disabilities (NICHCY) has identified the following characteristics and behaviors as typical of children with emotional disturbances:

- Hyperactivity (short attention span, impulsiveness)
- Aggression/self-injurious behavior (acting out, fighting)
- Withdrawal (failure to initiate interaction with others, retreat from exchanges or social interaction, excessive fear or anxiety)
- Immaturity (inappropriate crying, temper tantrums, poor coping skills)
- Learning difficulties (academically performing below grade level)

In addition, children with the most serious emotional disturbances may exhibit distorted thinking, excessive anxiety, bizarre motor acts, and abnormal mood swings.

It is important to note that many children who do not have an emotional disturbance may display some of these behaviors at different points in their development. The fundamental difference is that for children who have a serious emotional disturbance these behaviors continue over a long period of time demonstrating an inability to cope with their environment or peers.

Family Considerations

Families of children and youth experiencing a serious emotional disturbance may have difficulty accessing appropriate and timely services, particularly respite, due to the difficulty in finding appropriately trained respite providers. Respite providers need to know

- The characteristics of a serious emotional disturbance (from depression to manic behaviors)
- Behavior management principles and strategies;
- How to prevent escalation (not just how to de-escalate)
- Strategies to help prevent as well as manage a crisis situation (from aggressive acting out behavior to harming self or others to suicide attempts)

The high level of commitment, time, and energy required to provide constant supervision to these children should be explained to respite providers from the start.

Accessing respite and other family support services may also be hampered by the fact that children with serious emotional disturbances do not look "different" from other children. It is their behaviors that draw the attention. Young children with a serious emotional disturbance may be considered "bratty" or irritating. However, as children get older they are viewed as unruly, delinquent, out of control, mean, and even dangerous. The perceived cause is that they have not been taught or "made" to "mind," show respect, or learn responsibility. Providers and others need to understand that the behaviors are a symptom of the child's illness, not a result of poor parenting.

Unfortunately, families of children and youth with serious emotional disturbances have been blamed and held responsible for their child(ren)'s behavior. It is important for the community to understand that these families are doing the best they can under difficult circumstances. Because of this tendency to blame families, families often do not trust the human service system, and as a result, may not be perceived as cooperative and caring. It is important to recognize that families are often grieving over the loss of dreams for their child(ren).

Given this history with the service system, it is critical that families with children or youth experiencing a serious emotional disturbance be included in the development of services. Family participation can range from the development of their own child's service plan as an equal partner on their child's treatment team, to service delivery and service system assessment activities, to membership on statewide policy and planning groups.

Program Considerations

Referral Process

The definition that a program chooses will be the pivotal piece for determining if respite and/or other family support services are appropriate for that specific child/family. Programs may want to include in their intake procedures such questions such as these:

- Where is the child/youth currently living (i.e., natural or adopted family's home, foster home, etc.)?
- Is the child/youth eligible for respite or other services from other programs?
- Is the child/youth already receiving services and if so, what are they and who is delivering them?
- Is the child in imminent risk of removal from his/her home, in other words, is this a crisis situation?

Respite programs should receive referrals for respite from all participants in the local service delivery system: mental health, social and rehabilitation services, medical services, public schools, and families. Some programs may want to use an interagency team (consisting of representatives of all referring parties) to screen the referrals for appropriateness and then triage for delivery of respite.

In addition, a local interagency team can serve in an advisory board capacity to a respite program. In that role, the team may want to include a representative of the mental health agency. With this composition, the team can monitor the operation of the respite program, expanding on its successes and identifying the ongoing needs of the program. This team can also develop policies for the local respite program.

Matching of Respite Providers and Families

To insure the continuity of care, the matching of respite providers and families is critical. An effective matching process may take as many as three stages.

- The first stage is to make a match on paper. The strengths, interests, and values of the child and family are matched to the respite provider pool.
- In the second stage, the match is made in the home on a trial basis. This provides an opportunity for the child, family, and respite provider to gain familiarity and security with each other. It also sets up a flow of dialogue between the family and respite provider and follow-up dialogue with the respite coordinator. Perhaps most importantly, it allows the respite provider to be trained by the family in their own environment.
- The third stage concludes with a final match. Based on the information gathered from the application(s) and the success of the trial match, the final match between respite provider, child, and family is made. It is important that family members feel comfortable with the provision of care and that the respite provider feel comfortable and capable of managing the child's behavior. If either the family or respite provider is uncomfortable, it is best for all concerned to assign a different respite provider to the family.

Liability

Liability is a concern for both families and respite providers. Due to the intense needs of children and youth experiencing a serious emotional disturbance liability concerns escalate, particularly around behavioral issues.

Respite programs may want to consider the following strategies regarding this issue:

- First, it is important to decide if respite providers are to be employees of the provider agency or independent contractors. Agency employees will have to be covered under the umbrella of the agency's liability policy. In addition, it will be necessary for the respite program to provide on-call emergency back-up.
- Second, regular supervision by a respite coordinator will help to minimize crises and unforeseen situations. Regular supervision will also reduce respite provider burnout and turnover.
- Third, the provider agency may want to obtain release of liability forms signed by the family. While a waiver of liability is unlikely to provide protection in a court of law, it does give families and programs an opportunity to discuss the potential for accidents to occur during the provision of respite services.
- Fourth, the respite coordinator may want to inquire if any of the participating families carry liability coverage under their homeowner's policy.

Training

It is important for respite programs to incorporate family perspectives during the training of respite providers. While potential respite providers may

have had some experience working with children and youth experiencing a serious emotional disturbance, it is rare that their experience has taken them into a family's home over an extended period of time. It is a different dynamic when the service is delivered on the "family's turf." There are fears and expectations held by both the family and respite provider. While it may be the respite provider's first time in that home, it may be one of a dozen times the family has had an outsider intrude on their privacy.

To address some of these anxieties, it is recommended that a team approach be used in the training of respite providers. A mental health professional and a family member can co-facilitate the training and use service providers, siblings, and other family members as needed. As respite providers are assigned to particular families, it will be important for the family to provide information that is specific to their child's behavioral needs.

An ongoing discussion regarding confidentiality and boundary issues between family and respite provider needs to be weaved throughout the training of respite providers. Because having a child with a serious emotional disturbance is often blamed on the style of parenting that child receives, a family may feel they are under the microscope of the personnel and agencies from whom they receive services. Having a respite provider come into a family's home can feel intrusive and family members may feel violated. It will be important for respite providers to remember that things they see or hear in a family's home should not be shared with anyone (with the exception of issues of abuse or neglect). Establishing a level of trust between child, family, and respite provider will enhance the care that child receives and insure a trusting and meaningful relationship.

In addition, respite providers need to remember that their role is to provide a break for the family while establishing friendships with the children. The role of respite providers is not to "fix" what they perceive as deficient or wrong with the family. For example, if a family maintains a standard of living that does not feel appropriate or comfortable to the respite provider, it is not the role of the respite provider to try to enhance or raise that standard of living to their own satisfaction. That is an intrusion of the family and beyond the boundary of delivering respite. Of all issues covered regarding the delivery of respite care, issues of boundaries and confidentiality are violated most often. For this reason, it is critical to address these issues thoroughly throughout any training and supervision.

A basic training for respite providers should, at a minimum, cover the following areas:

- Overview of respite for children with serious emotional disturbances
- First Aid and CPR
- Defensive driving (if children will be transported–certification recommended.)
- Overview of psychotropic medications and administration procedures
- Emergency medical procedures and emergency protocols
- Behavior management and strategies
- Non-violent physical crisis intervention (restraint–certification recommended)
- Planning and providing quality activities for children
- Working with families
- Occupational Safety and Health Administration (OSHA) standards
- Liability issues
- Burnout prevention
- Confidentiality

Evaluation

As is the case for all types of respite programs, evaluation is a critical component when providing service to children and youth experiencing a serious emotional disturbance. As mentioned earlier, this group of youngsters has been severely under identified and under served. Longitudinal data needs to be developed to support the importance of respite for children with serious emotional disturbances, and the benefit to their families.

The evaluation of a respite program may take a two-prong approach. On one level, the local program collects ongoing data regarding use of the

service. The data collected may include an on-going evaluation of family, child, and worker satisfaction with the respite service; demographic characteristics of families who use and workers who provide respite; characteristics of the children/youth receiving the service; the hours of respite provided; and numbers of families on a waiting list. It is imperative for respite programs to develop a uniform method for tracking the number of families waiting to receive respite and the length of time they are on a waiting list. This is an invaluable piece of information in demonstrating the need to expand and enhance the program's capacity to provide respite.

Second, an outside (independent) annual evaluation may be desired. The independent evaluation can collect the agency's on-going data and present it in a format that will educate and motivate legislators and other potential funding sources to recognize the value of respite in maintaining family stability.

State Administration

It is helpful to have a state planning committee working to insure the continuation of respite for children and youth experiencing a serious emotional disturbance and their families. The planning committee should be comprised of representatives of those agencies that serve children and youth experiencing serious emotional disturbances and their families (mental health, social and rehabilitation services, medical services, public schools, and family members). The committee will receive, analyze, and disseminate evaluation information collected by local respite programs. The committee should also develop a long-range strategic plan for the continued funding and delivery of respite based on the results of the evaluation. The committee should also see themselves as educators to the legislature and community-at-large on the need and benefit of respite to families of children and youth experiencing a serious emotional disturbance.

Summary

Children and youth experiencing a serious emotional disturbance and their families have long been under identified and under served. Some parents of children with a serious emotional disturbance have been forced to give up custody of their child in order to obtain needed services, and in some states, residential placements may be a great distance from the child's home – sometimes out of the state. Because these children and youth often do not look psychologically deficient, expectation from service providers and the community-at-large is high. When the children do not meet these expectations, the blame may be inappropriately placed on their families. Respite can prevent a child or youth from being institutionalized and thus, separated from his/her family and community, but respite needs to be flexible, fluid, creative, and unconditional. In addition, families need to play an integral part in designing and implementing the program.

References

All Systems Failure: An Examination of the Results of Neglecting the Needs of Children with Serious Emotional Disturbance (1993). Prepared by Chris Koyanagi and Sam Gaines for The National Mental Health Association and The Federation of Families for Children's Mental Health.

General Information About Emotional Disturbance. NICHCY (National Information Center for Children and Youth with Disabilities), P.O. Box 1492, Washington, DC 20013-1492.

Diagnostic and Statistical Manual of Mental Disorders, 3rd revised ed. Washington, DC: American Psychiatric Association, 1987.

Knitzer, Jane (1982). *Unclaimed Children: The Failure of Public Responsibility to Children and Adolescents in Need of Mental Health Services.* Children's Defense Fund, Washington, D.C.

Vermont's System of Care. (1994). Department of Mental Health and Mental Retardation, Waterbury, VT.

Vermont Respite Care Demonstration Project (1989). Department of Mental Health and Mental Retardation, Waterbury, VT.

Wikler, L.M., Hanusa, D., Stoycheff, J. (1986). "Home-based respite care, the child with developmental disabilities, and family stress: Some theoretical and practical aspects of process evaluation." In Salisbury, C., and Intagliata, J. (Eds.), *Respite Care: Support for persons with developmental*

disabilities and their families, (pp. 243-261). Baltimore: Paul H. Brookes.

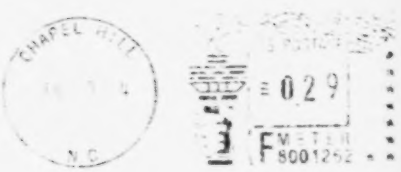
Resources

Center for Mental Health Services, Child, Adolescent, and Family Branch, 5600 Fishers Lane, Room 11C-09, Rockville, MD 20857, (301) 443-1333, FAX (301) 443-0541.

About the authors: Judith Sturtevant *is the mother of two, one of whom is experiencing a serious emotional disturbance. She is the founder and Director of the Vermont Federation of Families for Children's Mental Health, Montpelier, VT.*

Sandra Elliott *is the former director of the Family Respite Services of Overlook Center, Inc. Sandra has twenty-two years experience working with children and families.*

A special "*thank you*" to Gary DeCarolis, Director, Child, Adolescent, and Family Branch, Center for Mental Health Services, U.S. Department of Health and Human Services, for reviewing and providing input for the development of this factsheet.



ARCH
Chapel Hill Training-Outreach Project
800 Eastowne Drive, Suite 105
Chapel Hill, NC 27514

Council for Exceptional Children
1920 Association Drive
Reston, VA 22091

This fact sheet was produced by the ARCH National Resource Center for Crisis Nurseries and Respite Care Services funded by the U.S. Department of Health and Human Services, Administration for Children and Families, Administration on Children, Youth and Families, Children's Bureau—Cooperative Agreement No. 90-CN-0121 under contract with the North Carolina Department of Human Resources, Mental Health/Developmental Disabilities/Substance Abuse Services, Child and Family Services Branch of Mental Health Services, Raleigh, North Carolina. The contents of this publication do not necessarily reflect the views or policies of the funders, nor does mention of trade names, commercial products or organizations imply endorsement by the U.S. Department of Health and Human Services.

This information is in the public domain. Readers are encouraged to copy and share it, but please credit the ARCH National Resource Center.